

Racial Differences in Predictors of Intensive End-of-Life Care in Patients With Advanced Cancer

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See accompanying editorial on page 5496

ABSTRACT

Purpose

Black patients are more likely than white patients to receive life-prolonging care near death. This study examined predictors of intensive end-of-life (EOL) care for black and white advanced cancer patients.

Patients and Methods

Three hundred two self-reported black ($n = 68$) and white ($n = 234$) patients with stage IV cancer and caregivers participated in a US multisite, prospective, interview-based cohort study from September 2002 to August 2008. Participants were observed until death, a median of 116 days from baseline. Patient-reported baseline predictors included EOL care preference, physician trust, EOL discussion, completion of a Do Not Resuscitate (DNR) order, and religious coping. Caregiver postmortem interviews provided information regarding EOL care received. Intensive EOL care was defined as resuscitation and/or ventilation followed by death in an intensive care unit.

Results

Although black patients were three times more likely than white patients to receive intensive EOL care (adjusted odds ratio [aOR] = 3.04, $P = .037$), white patients with a preference for this care were approximately three times more likely to receive it (aOR = 13.20, $P = .008$) than black patients with the same preference (aOR = 4.46, $P = .058$). White patients who reported an EOL discussion or DNR order did not receive intensive EOL care; similar reports were not protective for black patients (aOR = 0.53, $P = .460$; and aOR = 0.65, $P = .618$, respectively).

Conclusion

White patients with advanced cancer are more likely than black patients with advanced cancer to receive the EOL care they initially prefer. EOL discussions and DNR orders are not associated with care for black patients, highlighting a need to improve communication between black patients and their clinicians.

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INTRODUCTION

The majority of Americans report wanting to die at home.^{1,2} However, a small percentage of patients who are terminally ill do not share the goal of going “gentle into that good night,” opting instead for intensive, life-prolonging care at the end of life (EOL). Frequently included in this group are black patients who both prefer³⁻¹⁸ and receive^{1,19-23} intensive EOL care at higher rates than white patients.

Efforts to understand the determinants of intensive EOL care among black patients have pointed to a set of interrelated hypotheses that highlight differences between black and white decision makers, including the following: black patient preferences for intensive care^{17,24}; distrust of physicians and

medical institutions in light of a history of racial discrimination and health disparities^{10,12,25}; the role of religion or spiritual beliefs in black patients coping with terminal illness²⁶⁻²⁸; inferior doctor-patient communication^{29,30}; and a lack of knowledge, appreciation, and/or use of advance care planning on the part of black patients.^{8,15}

Knowing whether differences exist in prospective predictors of life-prolonging care among black and white patients and the relative importance of these predictors to both groups may suggest priorities for clinician-patient communication and lead to patient-specific interventions to improve quality of life and care near death for black and white patients who are terminally ill. The present study used data from the Coping with Cancer cohort to examine and

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compare putative predictors of intensive EOL care among black and white patients who are terminally ill. Our hypotheses included the following: black patients with advanced cancer would prefer and receive more intensive EOL care than white patients with advanced cancer; however, patient preferences, discussions with a physician regarding EOL care, and the completion of advance care planning documents would be equally important to both groups in the prediction of receipt of intensive EOL. In contrast, we hypothesized that although the rate of physician trust would be equal in black and white patient samples, physician trust would be of greater importance in predicting foregoing intensive EOL care among black patients. Finally, religious coping was expected to be more common and more important in the prediction of intensive EOL care among black patients.

PATIENTS AND METHODS

Study Sample

Participants were self-reported black and white patients with advanced cancer and their caregivers recruited as part of the Coping with Cancer study. Participants were recruited between August 2002 and August 2008 from the following sites: Yale Cancer Center, New Haven, and Veterans Affairs Connecticut Healthcare System Comprehensive Cancer Clinics, West Haven (CT); Dana-Farber Cancer Institute and Massachusetts General Hospital Cancer Center, Boston (MA); Parkland Hospital Palliative Care Service, Parkland Health and Hospital System, and Simmons Comprehensive Cancer Center, University of Texas, Southwestern Medical Center, Dallas (TX); and New Hampshire Oncology-Hematology, Hookset (NH). During the study period, in- and outpatient hospice care was available at all study sites. Inpatient palliative care consultations were available for the majority of the study period at all sites except New Hampshire, whereas outpatient palliative care consults were not available at the majority of sites throughout the study. All study protocol and contact documents were reviewed and approved by the human subjects committee at each institution before the research was conducted, and all participants provided written informed consent.

Potentially eligible participants were identified by study staff at each institution via review of clinic patient lists. Inclusion criteria were as follows: diagnosis of advanced cancer (presence of distant metastasis); failure of first-line chemotherapy; diagnosis at a participating site; age 20 years or older; identified, informal caregiver; and adequate stamina to complete the interview. Patient-caregiver dyads were excluded if either refused to participate, met criteria for dementia or delirium using a mental status examination questionnaire,³¹ or could not speak English or Spanish.

Of the 944 patients who were initially approached and confirmed to be eligible, 274 (29.0%) declined participation. The most common reasons for nonparticipation included not interested ($n = 109$) and caregiver refusal ($n = 35$). Participants, compared with nonparticipants, were less likely to be distressed on a 5-point Likert scale whose extremes ranged from 1 (minimal/nonexistent) to 5 (distraught; mean score, 2.53 ± 2.94 , respectively; $P < .001$). There were no significant differences between nonparticipants and participants regarding sex, age, race, or education. Given the outcomes of interest, the sample was further limited to patients who had died ($n = 371$) with complete information on location of death ($n = 370$), self-reported black or white race ($n = 303$, those excluded reported other racial or ethnic backgrounds, the majority being self-identified as Hispanic), and complete information on at least four of the five predictors of interest, resulting in a total of 302 patients (68 black and 234 white patients).

Demographic and Health Measures

Patients and caregivers participated in separate interviews conducted by trained interviewers. Participants were asked sociodemographic questions and the EOL care questions described in the following section. Race was assessed with the question, "What race or ethnicity do you consider yourself to be?" Response options included white, black, Asian American/Pacific Islander/Indian, Hispanic, other, refused, and don't know.

The McGill Quality of Life (QOL) Questionnaire³² was used to assess QOL (higher scores represent better QOL). Patient mental health was measured using the Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders (ed 4) Axis I Modules.³³ Karnofsky performance score,³⁴ Charlson comorbidity index,³⁵ and cancer type were determined via chart review and confirmation with the patient's physician. Caregivers participated in a postmortem interview to determine whether cardiopulmonary resuscitation (CPR) and/or ventilation occurred in the last week of life and the location of death. If the caregiver was unable to complete the postmortem interview, we obtained this information from the medical chart ($n = 42$, 13.9%). In bivariate analysis, data collection from the chart was not associated with race ($P = .168$) or intensive EOL care ($P = .793$). All scales are psychometrically sound and have established reliability and validity.^{33,35-38}

EOL Care Predictors

The following five patient-reported baseline predictors were selected for analysis based on prior studies: patient preference for intensive EOL care,^{16,17} physician trust,^{6,10,12} doctor-patient EOL care discussion,^{29,30} completion of a Do Not Resuscitate (DNR) order,^{8,12,15} and positive religious coping.²⁶⁻²⁸ Having a preference for intensive EOL care was defined as answering "Extend life as much as possible" rather than "Relieve pain or discomfort as much as possible" to the following question: "If you could choose, would you prefer: 1. a course of treatment that focused on extending life as much as possible, even if it meant more pain and discomfort, or 2. on a plan of care that focused on relieving pain and discomfort as much as possible, even if that meant not living as long?"

The following questions (with response options of "yes" or "no") were asked to assess physician trust, having an EOL discussion, and having a DNR order, respectively: "Do you trust your doctors here?"; "Have you and your doctor discussed any particular wishes you have about the care you would want to receive if you were dying?"; and "Have you completed a Do Not Resuscitate (DNR) order?"

Religious coping was measured via Pargament's Brief Religious Coping Scale,³⁹ a previously validated questionnaire comprised of seven positive religious coping items (eg, "I've been looking for a stronger connection with God") and seven negative religious coping items. We focused on positive religious coping because few patients endorsed negative religious coping, making it a rare, unrepresentative coping style. Using a 4-point Likert scale (0 = not at all; 3 = a great deal), items were summed to yield an overall score (range, 0 to 21). Patients scoring at or above the median score of 12 were designated as positive religious copers based on prior research suggesting an association between race and receipt of intensive EOL care.⁴⁰

Outcome Measure

The primary outcome was intensive EOL care defined as CPR and/or ventilation within the last week of life followed by death in an intensive care unit (ICU). Selection of this end point targets those receiving the most aggressive EOL care and eliminates consideration of individuals who, for example, received a brief trial of ventilation and then elected to die at home or in hospice.

Statistical Analysis

Descriptive statistics were used to characterize the demographics of the study sample. t tests were used for continuous variables, Cochran-Mantel-Haenszel statistics were used for categorical variables, and χ^2 statistics for binary variables. Given the relatively small sample of black participants, all EOL care predictors were estimated in separate regression models. Logistic regression was used to determine the association between race and intensive EOL care and race and each EOL care predictor, using white patients as the reference group. Race-stratified logistic regression models were used to test the association of intensive EOL care with each EOL care predictor. All models were adjusted for confounders (entered into the model if related to the outcome measure bivariate at a significance level of $P < .10$). Results are presented as unadjusted odds ratios (ORs) and adjusted ORs (aORs). Where unadjusted and adjusted logistic models were not able to be performed because of zeroes in at least one cell, χ^2 statistics were used. Statistical inferences were based on two-sided tests. Data were analyzed with the SAS System for Windows version 9.1 (SAS Institute, Cary, NC).

RESULTS

Patient Characteristics

The sociodemographic and clinical characteristics of the 68 black and 234 white patients with advanced cancer are listed in

Table 1. On average, black patients were 5 years younger; less likely to be married, have a high school education, or be insured; and more likely to be recruited from our Texas sites. Black patients reported higher baseline scores on the existential and social support subscales of the McGill QOL Questionnaire.

Table 1. Patient Demographics and Clinical Characteristics by Racial Status (N = 302)

| Characteristic | Black Patients (n = 68) | | White Patients (n = 234) | | P |
|--|-------------------------|------|--------------------------|------|------|
| | No. | % | No. | % | |
| Age, years | | | | | .004 |
| Mean | | 55.7 | | 60.3 | |
| SD | | 10.9 | | 11.8 | |
| Male | 37 | 54.4 | 128 | 54.7 | .966 |
| Education, years | | | | | .000 |
| Mean | | 11.2 | | 13.8 | |
| SD | | 3.2 | | 3.0 | |
| Married | 19 | 27.9 | 143 | 61.9 | .000 |
| Religion | | | | | .000 |
| Catholic | 4 | 5.9 | 92 | 39.3 | |
| Protestant | 11 | 16.2 | 49 | 20.9 | |
| Baptist | 34 | 50.0 | 22 | 9.4 | |
| Other | 18 | 26.5 | 56 | 23.9 | |
| None | 1 | 1.5 | 15 | 6.4 | |
| Health insurance | 21 | 31.3 | 175 | 77.1 | .000 |
| Recruitment site | | | | | .000 |
| Yale Cancer Center | 9 | 13.4 | 63 | 27.0 | |
| West Haven VA Cancer Center | 2 | 3.0 | 16 | 6.9 | |
| Simmons Comprehensive Cancer Center | 4 | 6.0 | 29 | 12.5 | |
| Parkland Hospital | 52 | 77.6 | 49 | 21.0 | |
| Partners (DFCI, MGH) Cancer Centers | 0 | 0.0 | 9 | 3.9 | |
| New Hampshire Oncology-Hematology | 0 | 0.0 | 67 | 28.8 | |
| Cancer type | | | | | .191 |
| Lung | 19 | 28.4 | 55 | 23.8 | |
| Colon | 12 | 17.9 | 30 | 13.0 | |
| Breast | 7 | 10.5 | 21 | 9.1 | |
| Pancreas | 2 | 3.0 | 25 | 10.8 | |
| Hematologic | 1 | 1.5 | 15 | 6.5 | |
| Other | 26 | 38.8 | 85 | 36.8 | |
| Karnofsky performance score | | | | | .023 |
| Mean | | 66.0 | | 61.3 | |
| SD | | 12.7 | | 19.1 | |
| Charlson comorbidity index | | | | | .763 |
| Mean | | 6.5 | | 6.6 | |
| SD | | 1.6 | | 2.5 | |
| SCID diagnosis | 5 | 7.4 | 25 | 11.2 | .365 |
| McGill Quality of Life Questionnaire score | | | | | |
| Physical domain | | | | | .632 |
| Mean | | 5.6 | | 5.5 | |
| SD | | 1.6 | | 1.3 | |
| Psychological domain | | | | | .081 |
| Mean | | 2.4 | | 3.0 | |
| SD | | 2.6 | | 2.5 | |
| Existential domain | | | | | .003 |
| Mean | | 8.2 | | 7.4 | |
| SD | | 1.7 | | 1.9 | |
| Support domain | | | | | .020 |
| Mean | | 9.0 | | 8.5 | |
| SD | | 1.5 | | 1.8 | |

NOTE. Data were missing for patients in the following categories: married (n = 3), insured (n = 8), recruitment site (n = 2), cancer type (n = 4), Karnofsky performance score (n = 14), Charlson comorbidity index (n = 12), SCID diagnosis (n = 10), and McGill Quality of Life Questionnaire score (n = 2).

Abbreviations: SD, standard deviation; VA, Veterans Affairs; DFCI, Dana-Farber Cancer Institute; MGH, Massachusetts General Hospital; SCID, Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders (ed 4).

Table 2. Racial Differences in the Rates of Patient-Reported Predictors of EOL Care at Baseline (N = 302)

| EOL Care Predictors | Black Patients (n = 68) | | White Patients (n = 234) | | Unadjusted | | Adjusted* | |
|-----------------------------------|----------------------------|------|-----------------------------|------|------------|------|-----------|------|
| | No. | % | No. | % | OR† | P | OR† | P |
| Physician trust | 67 | 98.5 | 229 | 98.7 | 0.88 | .422 | 0.36 | .456 |
| Positive religious coping | 57 | 83.8 | 76 | 32.5 | 10.77 | .000 | 4.00 | .005 |
| EOL discussion | 24 | 35.3 | 89 | 38.4 | 0.88 | .646 | 0.76 | .474 |
| Preference for intensive EOL care | 25 | 36.8 | 50 | 21.6 | 2.12 | .012 | 1.93 | .034 |
| DNR order | 21 | 30.9 | 115 | 50.4 | 0.44 | .005 | 0.38 | .011 |

NOTE. Data were missing for patients in the following categories: physician trust (n = 2), EOL discussion (n = 2), preference for intensive EOL care (n = 2), and DNR order (n = 6).

Abbreviations: EOL, end of life; OR, odds ratio; DNR, do not resuscitate.

*OR for physician trust was adjusted for Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders (ed 4) diagnosis, Charlson comorbidity index, and McGill Psychological, Support, and Existential domain scores. OR for positive religious coping was adjusted for age, education, married, religion, insured, recruitment site, cancer type, Karnofsky performance score, Charlson score, and McGill Existential and Support Domain scores. OR for EOL discussion was adjusted for recruitment site, Karnofsky performance score, and McGill Psychological Domain score. OR for preference for intensive EOL care was adjusted for age and sex. OR for DNR order was adjusted for age, recruitment site, cancer type, Charlson score, and Karnofsky performance score.

†White patients are the reference group.

Racial Differences in EOL Care

More black patients (13.2%) received intensive EOL care (ventilation and/or CPR and died in the ICU) compared with white patients (3.4%). After controlling for age, sex, and the McGill support domain, black patients remained three times more likely than white patients to receive intensive EOL care (aOR = 3.04, $P = .037$). Patients receiving intensive EOL care were in the ICU for a median of 3 days before death (range, 1 to 21 days).

Predictors of EOL Care by Racial Status

At baseline, black patients were more likely to prefer intensive EOL care (aOR = 1.93; $P = .034$) and less likely to have a DNR order (aOR = 0.38, $P = .011$; Table 2). Black patients were equally as likely as their white counterparts to report having had an EOL discussion with their physician (aOR = 0.76, $P = .474$) and to report trusting their physician (aOR = 0.45; $P = .364$). Nearly 84% of black patients were positive religious copers. After controlling for confounders, black patients remained four times more likely than white patients to report positive religious coping (aOR = 4.00; $P = .005$).

Differential Effect of EOL Care Predictors on Care Received by Racial Status

In analyses stratified by race, white patients who preferred intensive EOL care were approximately three times more likely to receive this care than black patients with the same preference (aOR = 13.20, $P = .008$ v aOR = 4.46, $P = .058$; Table 3). White patients who reported either an EOL discussion or having a DNR order did not receive intensive EOL care. Among black patients, similar reports did not significantly prevent intensive EOL care in the last week of life.

The uniformly high rate of physician trust in both groups prevented calculation of ORs for this predictor after stratification (because of empty cells). Finally, the magnitude of the association of religious coping and receipt of intensive EOL care was approximately four-fold higher in white patients (aOR = 7.76, $P = .025$ v aOR = 1.78, $P = .617$ for black patients).

DISCUSSION

This study investigated the rate and predictors of intensive EOL care among black and white patients who are terminally ill. We found that

Table 3. Differences in the Association of EOL Care Predictors and Receipt of Intensive Care Near Death, Stratified by Racial Status

| EOL Care Predictors | All Patients (N = 302) | | | | Black Patients (n = 68) | | | | White Patients (n = 234) | | | |
|-----------------------------------|------------------------|------|----------|------|-------------------------|------|----------|------|--------------------------|-------|----------|------|
| | Unadjusted | | Adjusted | | Unadjusted | | Adjusted | | Unadjusted | | Adjusted | |
| | OR | P | OR | P | OR | P | OR | P | OR | P | OR | P |
| Physician trust | 0.17 | .136 | | | | | | | | | | |
| Positive religious coping | 6.51 | .004 | 4.12 | .048 | 1.63 | .661 | 1.78 | .617 | 6.69 | .022 | 7.76 | .025 |
| EOL discussion | 0.21 | .039 | 0.19 | .035 | 0.48 | .386 | 0.53 | .460 | 0.00 | .023* | —† | |
| Preference for intensive EOL care | 6.27 | .001 | 4.65 | .006 | 4.21 | .059 | 4.46 | .058 | 6.63 | .012 | 13.20 | .008 |
| DNR order | 0.14 | .011 | 0.15 | .017 | 0.60 | .549 | 0.65 | .618 | 0.00 | .004* | —† | |

NOTE. ORs for all patients were adjusted for age, sex, McGill Support domain score, and race. ORs for black patients were adjusted for Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition diagnosis. ORs for white patients were adjusted for sex, education, Charlson comorbidity index, and McGill Support domain score.

Abbreviations: EOL, end of life; OR, odds ratio; DNR, do not resuscitate.

* χ^2 test.

†Indicates that no white patient with this predictor experienced intensive EOL care, preventing calculation of adjusted OR.

black patients were three times more likely to experience intensive EOL care and approximately two times more likely to prefer this type of care than their white counterparts. Despite the disproportionate preference for intensive EOL care among black patients, white patients who preferred intensive EOL care were nearly three times more likely to receive it than black patients with the same preference.

Instability in the EOL care preferences of black patients as death approaches may be one explanation for these findings.¹⁴ Some observers have suggested that black patients may be reticent to express a preference for comfort care early in an illness given fears that clinicians may withhold treatment or give up too quickly.²⁴ As death approaches, this fear may diminish, allowing black patients to share their desire for palliative care. Alternatively, given that the majority of white patients support a palliative approach to terminal illness, white patients who do not may be more committed to, and expressive of, their preference for intensive care than black patients with a similar inclination at baseline.

Greater attention to patient autonomy among the caregivers and clinicians of white patients may also explain why no white patients who reported either an EOL discussion or a DNR order at baseline received intensive care in the last week compared with black patients. Further investigation of the two instances in which black patients reported having a DNR order at baseline and yet received intensive EOL care in the last week of life suggested that one or more of the following factors may have played a role: a different informal caregiver than the patient's usual informal caregiver was present at the time of clinical deterioration, a lack of awareness of the DNR order by informal caregivers and/or clinicians, and placement in a facility other than the one providing the patient's primary oncology care at the time of terminal hospitalization. This suggests that social forces, beyond the immediate oncologist-patient interaction, may play a larger role in determining EOL outcomes for black patients than for white patients.

Social forces may also explain the results for EOL care conversations. The lack of association of these conversations with receipt of EOL care among black patients is not attributable to a difference in the rate of conversations in the two groups, which were equivalent. Instead, the dilution of the effect of EOL conversations on intensive EOL care among black patients may be as a result of differences in the patient-physician communication process. To counteract this, clinicians may elect to discuss black patient preferences more frequently as the illness progresses and discuss the elicited preferences with caregivers (with particular attention to extended family and friends). They might also devise plans to ensure that treatment preferences are known and documented so that they can be respected should an unanticipated medical crisis occur (eg, 911 calls, being taken to an alternative facility, caregiver fear or confusion). Knowing in greater detail the content of the EOL conversations between physicians and black patients, as well as the timing of the conversation relative to the patient's diagnosis (eg, black patients tend to be diagnosed later in the course of their illness^{41,42}) and differences in the events leading up to death, would further our understanding of how clinical communications influence racial differences in receipt of EOL care.

Finally, positive religious coping was expected to be of greater importance to black rather than white patients in predicting receipt of intensive EOL care. Although positive religious coping was endorsed by a significantly greater number of black patients, it was not associated with more intensive EOL care among black patients. However, this result should not be misinterpreted as suggesting that religious coping is unimportant to black patients. On the contrary, black pa-

tients had higher levels of positive religious coping relative to white patients, and this uniformly high degree of religious coping (and therefore, less variability in this study) may contribute to a lack of predictive power. In other words, positive religious coping was better able to explain why a white patient would receive intensive EOL care than a black patient because most black patients were positive religious copers. Differences in religious traditions or practices may also account for the observed differences in the effect of positive religious coping by race. Future research is needed to examine this possibility.

Further research should also investigate racial differences in levels of existential and social support-related QOL at EOL. Black patients frequently report high levels of religious affiliation and spirituality, as they did in this study.^{28,43,44} This finding, in conjunction with evidence that the existential domain of the McGill QOL Questionnaire is highly correlated with overall QOL near death among patients with advanced cancer,³² suggests that cultural differences in spirituality, religious coping, and social support may benefit black patients who are nearing death more than white patients. This stands in contrast to racial differences in health-related QOL generally.⁴⁵

Given the relatively small sample of black patients, future research is needed to replicate these findings in a larger, more heterogeneous sample. Doing so would allow for testing of a fully adjusted model and/or interaction terms and a more complete accounting of geographic area-based effects on patient preferences and care received (eg, clustered analysis or geocoding). This study did not measure clinician awareness of the patients' preferences or provide clinicians information regarding the patients' preferences, limiting our ability to comment on these issues. However, clinician awareness of the study would likely increase, rather than decrease, interest in patient preferences and EOL care. We also do not have information regarding transfers between facilities or the role or availability of primary care physicians. Finally, participants must have agreed to participate in the study, and although participants did not significantly differ from nonparticipants with respect to measured demographic variables, it is unknown whether participants differed from nonparticipants with respect to their preferences for intensive EOL care or the care they ultimately received.

Despite these limitations, this study represents one of the most detailed, quantitative evaluations of prospective predictors of EOL care among black and white patients who are terminally ill to date. It demonstrates important influences on the receipt of intensive EOL care among white patients with advanced cancer and highlights the racially disparate effects of these variables on EOL care, reinforcing the need for future research to understand which factors are important and predictive in black patients' EOL decision making to inform clinical practice, improve communication, and ensure quality EOL care.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

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